Lifelong Care for Children with Chronic Conditions:
A discussion series

Re-imagining the Package of Care for Children Subgroup

May 14, 2021
Child Health Task Force Today

1500+ members
from
50+ countries
300+ organizations

Working together in 10 subgroups

Coordination
Support
Countries
Knowledge
Management

Advocacy
Learning

Focused on 5 themes of work
Series objectives

• Share and get feedback on UNICEF’s working “Integrated Chronic Lifelong Care for Children and Adolescents” framework

• Present case studies on specific chronic conditions

• Draw lessons for broader programming and implementation
Nande Putta
Program Specialist
Child Survival
UNICEF

Bistra Zheleva
VP Global Strategy and Advocacy, Children’s HeartLink

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HQ State Nodal Officer Child Health, National Health Mission.
Department of Health, Kerala
Integrating Chronic Lifelong Care for Children and Adolescents in Primary Health Care

Dr. Nande Putta

May 2021
Presentation Outline

- Rationale
- Framing in the broader context of Child Health Epidemiology and PHC
- Conceptual Graphic of the Chronic Care Model (CCM) for Children and Adolescents
- Ongoing processes towards guidance development
Rationale

• Chronic Conditions affecting Children and Adolescents: HIV, Diabetes, Rheumatic Heart Disease, Asthma, Disabilities, Sickle Cell Disease, Cancers, Hep B, Syphilis

• In contrast with high-income countries, Chronic Care for children and adolescents is a less-developed area in low-and-middle-income countries

• These countries have typically focused on “episodic” management of common childhood illnesses that significantly contribute to child mortality

• With shifting epidemiologies, in part due to improving economies and gains in child mortality; and with UNICEF’s focus on a thrive and transform agenda over and above survival; chronic conditions come more into focus.
DALY’s by NCDs, Injuries, and communicable/nutritional disorders in the 1st two decades of life

<table>
<thead>
<tr>
<th>Country Type</th>
<th>&lt;5 Years</th>
<th>5-19 Years</th>
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<tr>
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<tr>
<td>LMIC</td>
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<td>UMIC</td>
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<td>LIC</td>
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<tr>
<td>PB</td>
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</table>

Burden of diseases/disorders and NCDIs varies by economic income.
Embedding Chronic Lifelong Care Models for Children & Adolescents in PHC

Well Child and Adolescent

Acutely sick or afflicted Child and Adolescent

Chronically sick or afflicted Child and Adolescent

HEALTH & WELL-BEING

Primary care & essential public health functions as the core of integrated health services

Multifaceted policy & action

Empowered people & communities
LIFECOURSE

Pregnancy Birth Infancy (0-1 yrs) Early Childhood (1-4yrs) Middle Childhood (5-9) Adolescence (10-19)

Community, Civil Society & Multi-Sectoral engagement
Health literacy (awareness raising, prevention messaging) for chronic diseases
Early detection of risk and referral
Peer and treatment support

Specialized care e.g. surgery, chemo/radiotherapy
Management of complicated cases, treatment failures

Routine entry points

ANC Immunization Immunization, well and sick baby clinics, nutrition services School & health services

Community, Civil Society & Multi-Sectoral engagement
Health literacy (awareness raising, prevention messaging) for chronic diseases
Early detection of risk and referral
Peer and treatment support

Screening in pregnancy (HIV, SCD, CHD, CS)
Newborn screening for genetic metabolic conditions

Early screening, detection and diagnosis
Early interventions (Asthma, CHD, Childhood cancer, Congenital Syphilis, Developmental Delays & Disabilities, HIV, RHD, T1 & T2 diabetes)

Transition of care
Adherence risk management
Adolescent friendly services

Developmental monitoring, treatment monitoring & longitudinal tracking

Primary care

Primary health facility level

Community level
Health Systems Strengthening

- **Quality of Care**
  - Developmental monitoring, treatment monitoring & longitudinal tracking

- **Supply Chain Management**
  - ANC, Immunization, baby clinics, nutrition services

- **Health Workforce**
  - School & health services

- **Data and Digital Health**
  - Community, Civil Society & Multi-Sectoral engagement
  - Health literacy (awareness raising, prevention messaging)

- **Governance and Partnerships (CSO, Pvt. Sector)**
  - District HSS and decentralized management

- **National and Sub-national financing**
  - Health literacy (awareness raising, prevention messaging)

- **District HSS and decentralized management**
  - Supply Chain Management

- **Specialized Care**
  - Routine entry points
  - Health literacy (awareness raising, prevention messaging)

- **Primary Care**
  - Primary health care facility level

- **LIFECOURSE**
  - Pregnancy, Birth, Infancy (0-1 yrs)
  - Early Childhood (1-4 yrs)
  - Middle Childhood (5-9)
  - Adolescence (10-19)

- **Routine entry points**
  - Community, Civil Society & Multi-Sectoral engagement
  - Health literacy (awareness raising, prevention messaging)

- **Quality of Care**
  - Developmental monitoring, treatment monitoring & longitudinal tracking

- **Supply Chain Management**
  - ANC, Immunization, baby clinics, nutrition services

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- **Specialized Care**
  - Routine entry points
  - Health literacy (awareness raising, prevention messaging)
Overview of process underway

- Evidence review
- External Expert Group
- Partnership building
- Resource mobilization
- Webinar series
- Stakeholder consultation
- Early country level work across diverse countries

Thank You!
CONGENITAL HEART DISEASE - A CASE FOR POPULATION HEALTH APPROACH

Bistra Zheleva
Children’s HeartLink

May 2021
Children’s HeartLink

**Vision:** Children around the world have access to high-quality heart care

**Mission:** We save children’s lives by transforming pediatric heart care in underserved parts of the world
2030 Targets:

① End preventable childhood deaths
   - NM, 12 per 1,000 live births
   - U5M 25 per 1,000 live births

② Reduce by 1/3 premature mortality from NCDs

③ Achieve UHC, including financial risk protection

④ Substantially increase health workforce in LMICs
Child mortality by income level of country, 1990 to 2017

The child mortality rate measures the share of children that die before reaching the age of 5.

Source: World Bank
Decreasing U5MR Will Reveal the Constant Burden of Heart Disease

Under-5 Mortality Rate from All Causes

- 9% in 1990
- Projected to 4.6% in 2015
- 2.3% in 2030

Children Born with Heart Disease

- 0.8% in 1990
- Projected to 0.8% in 2030
# Causes of death in children >1 year, 2019

(by death rate per 100,000)

<table>
<thead>
<tr>
<th>Cause</th>
<th>WHO HI</th>
<th>WHO U</th>
<th>WHO UMI</th>
<th>WHO U</th>
<th>Earth</th>
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*GBDcompare tool, 2019 data*
THE GLOBAL BURDEN OF CONGENITAL HEART DISEASE

217,000 deaths from CHD globally

13.3 million prevalence

18.6 million DALYs

96% deaths in LMICs

70% (150,000) deaths were in infants

GBDcompare tool, 2019 data
<table>
<thead>
<tr>
<th>Condition</th>
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<th>Sri Lanka</th>
<th>Indonesia</th>
<th>China</th>
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<td>37</td>
<td>30</td>
<td>62</td>
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India CHD deaths, 2019
Total: 38,152
<1 year: 26,600
Neonatal: 16,718
NCD mortality beyond SDG target 3.4

WHO 25×25 target & SDG 3.4 → deaths from NCDs 30-70 age

2016

▲ 12.5 million deaths (30-70)
▲ 1.7 million deaths in <30 years of age

Largest NCD-related cause: congenital heart anomalies (~ 230,000)

Ahead of by several factors: sickle cell disorders, ischemic heart disease, stroke, kidney diseases, and leukemia
RHD and CHD: Global YLDs and YLLs by Age, 2017

Aggregate Data

YLDs
- RHD: 1,900,974
- CHD: 589,479

YLLs
- RHD: 7,492,586
- CHD: 21,634,418

Zimmerman et al. Lancet CAH, 2020
7% world population has access to cardiac surgery

90% no CHD treatment or suboptimal care

### Table 4. Ratio of Cardiac Surgeons to Population on Different Continents

<table>
<thead>
<tr>
<th>Continent</th>
<th>Ratio cardiac surgeons:population</th>
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<tbody>
<tr>
<td>North America</td>
<td>1:3.5 million</td>
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<tr>
<td>Europe</td>
<td>1:3.5 million</td>
</tr>
<tr>
<td>South America</td>
<td>1:6.5 million</td>
</tr>
<tr>
<td>Asia</td>
<td>1:25 million</td>
</tr>
<tr>
<td>Africa</td>
<td>1:38 million</td>
</tr>
</tbody>
</table>
The Cape Town Declaration on Access to Cardiac Surgery in the Developing World

Peter Zilla, MD, PhD, R. Morton Bolman, MD, Magdi H. Yacoub, MD, Friedhelm Beyersdorf, MD, Karen Sliwa, MD, PhD, Liesl Zühlke, MBChB, PhD, Robert S. D. Higgins, MD, Bongani Mayosi, MD, Alain Carpentier, MD, and David Williams, PhD

Christiaan Barnard Division of Cardiothoracic Surgery, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa; Division of Cardiothoracic Surgery, University of Vermont, Burlington, Vermont; Chain of Hope, Chelsea, London, United Kingdom; Department of Cardiovascular Surgery, Universitäts-Herzzentrum Freiburg–Bad Krozingen, Freiburg, Germany; Hatter Institute of Cardiovascular Research in Africa, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa; Pediatrics and Child Health, University of Cape Town, Cape Town, South Africa; College of Medicine, University of Cape Town, Cape Town, South Africa; and Wake Forest Institute of Regenerative Medicine, Winston-Salem, North Carolina, United States.

The Mission: To urge all relevant entities within the international community to commit to develop and implement an effective health-care system through increased access to life-saving cardiac surgery.

Global Unmet Needs in Cardiac Surgery


FIGURE 2. World map highlighting the contributing countries. In the circles, the number of cardiac surgeons per million population are depicted for each country.
# Pediatric Cardiac Care in an Ideal Health System

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Continuum of Care</th>
<th>Village Health Center</th>
<th>First-Level Hospital</th>
<th>Second-Level Hospital</th>
<th>Third-Level Hospital</th>
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<tr>
<td>Prenatal care and attended birth</td>
<td>Early Detection</td>
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<tr>
<td>Universal screening and referral</td>
<td>Early Detection</td>
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<td>Pulse oximeter</td>
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<td>Echocardiogram, electrocardiogram, and chest x-ray</td>
<td>Diagnosis</td>
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<td>Fetal echocardiogram</td>
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<td>Cardiac catheterization</td>
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</table>
# Pediatric Cardiac Care Continuum

with associated decision factors (and decision makers)

<table>
<thead>
<tr>
<th>Recognition</th>
<th>Diagnosis and prioritization</th>
<th>Referral</th>
<th>Stabilization and transport</th>
<th>Treatment</th>
<th>Follow-up</th>
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<tbody>
<tr>
<td>Prenatal Screening (OBGYN)</td>
<td>Emergent cases <em>(critical CHD)</em></td>
<td>Acuity</td>
<td>Safe transport of emergent and urgent cases</td>
<td>Surgery Treatment / Recovery</td>
<td>Short-term Follow-Up</td>
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<tr>
<td>Newborn pre-discharge screening</td>
<td>Urgent cases <em>(noncritical significant CHD)</em></td>
<td>Geography</td>
<td>Tracking and timely assessment of elective cases</td>
<td>Cath Lab Treatment / Recovery</td>
<td>Lifelong Follow-Up</td>
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<tr>
<td>Outpatient infant care symptom recognition</td>
<td>Elective cases <em>(insignificant CHD)</em></td>
<td>Bed availability</td>
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<tr>
<td></td>
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<td>Tiers of expertise</td>
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</tbody>
</table>

- Pediatrician
- Delivery center staff nurse
- RBSK nurse
- OBGYN
- Communities/Family

- Pediatric cardiologist
- Cardiologist

- Pediatric cardiologist
- RBSK nurse

- Referring facility
- Transport team

- Tertiary referral center pediatric cardiac team

- Pediatric cardiologist
- Pediatrician
- Community health worker/nurse

Zheleva, Int. J. Neonatal Screen. 6, 49; 2020
POPULATION HEALTH APPROACH TO CHD

Improving timely screening, diagnosis and referral, increase access to tertiary care
Kerala

SDG3: Reduce child mortality 2/3 by 2020 and 50% by 2030

<table>
<thead>
<tr>
<th></th>
<th>To 2020</th>
<th>To 2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>NMR</td>
<td>7 to 5</td>
<td>3</td>
</tr>
<tr>
<td>IMR</td>
<td>12 to</td>
<td>6</td>
</tr>
<tr>
<td>U5M R</td>
<td>14 to</td>
<td>7</td>
</tr>
</tbody>
</table>

Catalyst: RBSK, national 0-18 screening and intervention program for diseases, defects at birth & disabilities (Rashtriya Bal Swasthya Karyakram)

Malaysia

- Build pediatric cardiac surgery in the public sector
- Reduce reliance on private and semi-private providers
- Regionalize pediatric cardiac surgery
HRIDYAM

• *For Little Hearts* ...
Kerala's IMR was stagnant around 12 over a decade.

As per SRS 2019, IMR Kerala is now down to 7 per 1,000 live births.

**India has registered a significant decline in Infant Mortality Rate (IMR) in the last two decades.**

As per SRS 2019, IMR of India has declined to 32 per 1000 live births.

**Kerala Scenario**

Kerala's IMR was stagnant around 12 over a decade.

As per SRS 2019, IMR Kerala is now down to 7 per 1,000 live births.

- This reduction in IMR in Kerala is a result of efforts in bringing down anaemia among pregnant women, crucial interventions in the treatment of infectious disease among Newborn & infants, improved breast-feeding practises, better sanitation & hygiene, etc.
Why CHD has been given importance under IMR reduction strategy

IMR in Kerala while examined in detail revealed that Prematurity & Birth Asphyxia followed by Congenital Anomalies are the leading cause.

Among the congenital anomalies *Congenital Heart Disease* is the major contributor.
<table>
<thead>
<tr>
<th><strong>33 MILLION</strong></th>
<th>POPULATION, 14 ADMIN. UNITS (DISTRICTS)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>0.5 MILLION EST.</strong></td>
<td>CHILDREN BORN/YEAR</td>
</tr>
<tr>
<td><strong>12</strong></td>
<td>INFANT MORTALITY RATE, PER 1,000 LIVE BIRTHS</td>
</tr>
<tr>
<td><strong>6,000 EST.</strong></td>
<td>INFANT DEATHS/YEAR</td>
</tr>
<tr>
<td><strong>8 PER 1,000 EST.</strong></td>
<td>CHD INCIDENCE</td>
</tr>
<tr>
<td><strong>4,000 EST.</strong></td>
<td>NEW CHD/YEAR</td>
</tr>
<tr>
<td><strong>1,000-1,200 EST.</strong></td>
<td>NEW CRITICAL CHD/YEAR (25-30% OF ALL NEW CHD)</td>
</tr>
<tr>
<td><strong>650-750 EST.</strong></td>
<td>INFANT DEATHS FROM CHD/YEAR</td>
</tr>
<tr>
<td><strong>500 EST.</strong></td>
<td>ANNUAL KERALA-BORN INFANT CHD SURGERIES PERFORMED</td>
</tr>
<tr>
<td><strong>42-50 % EST.</strong></td>
<td>ESTIMATED INFANT SURGICAL TREATMENT COVERAGE</td>
</tr>
<tr>
<td><strong>7</strong></td>
<td>EXISTING PEDIATRIC CHD SURGERY CENTERS, 2 PUBLIC AND 5 PRIVATE</td>
</tr>
<tr>
<td><strong>12</strong></td>
<td>PEDIATRIC CARDIOLOGISTS</td>
</tr>
<tr>
<td><strong>10</strong></td>
<td>PEDIATRIC CARDIAC SURGEONS</td>
</tr>
</tbody>
</table>
MILE STONES..

**Metabolic Screening**
Started as a special initiative in selected delivery points

**Pulse Oximetry Screening**
Started in selected 54 delivery points (with more than 100 delivery per month) for early detection of cCHD

**Hearing (OAE) Screening**
OAE Screening program started with the support of KSSM, Presently, extended to all Delivery points with more than 50 delivery per month

**VBD screening as part of RBSK**
As part of rolling out RBSK, documenting Newborn Birth defect screening in delivery points were initiated

**ROP Screening for High Risk Preterm**
Screening for Retinopathy of Prematurity started in 7 Tertiary Care Special Newborn Care Units

**2012**

**2014**

**2016**

**2018**
FUNCTIONAL BIRTH DEFECT SCREENING

Pulse Oximetry screening for Congenital Heart Disease at all 98 Public Delivery points

- **Pulse Oximetry Screening for CHD**
  - PO Screening at 24-48 Hours after birth & the set algorithm in machine detects PO passed/failed

- **PO Results to Hridyam portal**
  - Machine while connected to local computer with Internet Connectivity PO results against each child get updated in Hridyam & VBD portal

- **Combined with Physical Examination**
  - All failed cases by send to Pediatrician for specifically looking for any HEART MURMUR & LOW Vol FEMORAL PULSE

- **Pulse Oximetry linked to HRIDYAM**
  - Failed cases will be alerted to DEIC who will arrange for confirmatory ECHO. The case will get registered in Hridyam and case followed up.

Hridyam Portal
Focus is on Infant Cases/ Neonates with complex diseases as a life saving program.

<table>
<thead>
<tr>
<th>Sl. No.</th>
<th>INSTITUTIONS</th>
<th>2020</th>
<th>2019</th>
<th>2018</th>
<th>2017</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>SCTIMST</td>
<td>148</td>
<td>330</td>
<td>439</td>
<td>171</td>
</tr>
<tr>
<td>2</td>
<td>MCH KOTTAYAM</td>
<td>23</td>
<td>86</td>
<td>108</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>MCH KOZHIKKODE</td>
<td>4</td>
<td>13</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>4</td>
<td>AIMS Cochin</td>
<td>357</td>
<td>298</td>
<td>225</td>
<td>16</td>
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<td>5</td>
<td>Aster Medicity, Ernakulam</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>Lissie Hospital</td>
<td>234</td>
<td>85</td>
<td>49</td>
<td>13</td>
</tr>
<tr>
<td>7</td>
<td>Aster MIMS, Kozhikode</td>
<td>199</td>
<td>127</td>
<td>22</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>Believers Church Medical College</td>
<td>42</td>
<td>49</td>
<td>42</td>
<td>7</td>
</tr>
<tr>
<td>9</td>
<td>SAT THIRUVANANTHAPURAM (Only interventions)</td>
<td>11</td>
<td>40</td>
<td>45</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>1021</strong></td>
<td><strong>1031</strong></td>
<td><strong>930</strong></td>
<td><strong>208</strong></td>
</tr>
</tbody>
</table>
Follow up of Hridyam Cases in Community

Case Registered in Hridyam portal

Pre-Surgical Case
Cases redistributed as per their local area, So that the community Nurse can see the case in their login
Case is followed up as per predefined schedules, at least once in every month
Will document the findings as per the designed format digitally real-time
Response initiated by treating team in case of emergencies through Hridyam portal

Post-Surgical Case
Case followed up as per pre-defined protocol. First visit after 72 hours post discharge, 7th day, 14 days, 1 month, 3 months and 6 months or as recommended by treating team
Action initiated as per the need of the case.
The Main Success Factors are:

- Uniqueness, Importance & Focus

**Uniqueness**

- **First of this kind** - comprehensive approach to Children with Congenital Heart Disease (CHD).
- **Cashless Treatment** in Private empanelled Hospitals.
- **Web based Single registry**
  For children with CHD – Case, pre surgical and post surgical follow up

**Focus**

- **Thrust given to early Diagnosis** - various means Ante natal Fetal Heart Screening, Pulse Oximetry combined with physical examination.
- **Capacity building - Technical and Infrastructure** is also taken up as a comprehensive program

**Importance**

- All surgical slots in Kerala made into a single pool & available for children registered under Hridyam
- **Waiting period became finite**
  Those registered knows their tentative surgery dates
Engage with the co-chairs:

- Cara Endyke Doran - cendykedoran@globalcommunities.org
- Raoul Bermejo - rbermejo@unicef.org

Series Dates & Case Study Discussions:

- **May 14th**: Congenital heart disease
- **June 11th**: HIV, type 1 diabetes & sickle cell disease
- **July 9th**: Integrated NCD package of services

**Time**: 9 - 10:30am EDT [GMT-4]

Check out the Child Health Task Force Website for important resources!

Subgroup information, recordings and presentations from previous webinars are available on the subgroup page of the Child Health Task Force website:

[www.childhealthtaskforce.org/subgroups/expansion](http://www.childhealthtaskforce.org/subgroups/expansion)

Become a member of the subgroup: [www.childhealthtaskforce.org/subscribe](http://www.childhealthtaskforce.org/subscribe)